

March 18, 2009

My 5 year old son, Dylan, was diagnosed with a sensorineural hearing loss when he was 3 ½ years old. He was ultimately diagnosed with his hearing loss through a sedated Auditory Brainstem Response (ABR) test. Dylan was still under sedation when the audiologist informed us of the severity of his hearing loss and without hesitation she then preceded to tell us that most likely our insurance carrier would not pay for his hearing aids. So as we were trying to grasp the concept that our child had not been hearing us, now we were being told the tools he needed to help him hear would most likely not be covered by our insurance coverage. And she was correct. Our insurance carrier denied him hearing aids. We could not understand why our insurance company was denying him the tools that we were told would help him hear and develop language.

My family was fortunate to be at Children's Hospital where in just a matter of weeks he was fitted with his first pair of hearing aids. Dylan quickly went from saying a few new words to forming sentences all because he had the tools to help him hear and verbally communicate. He adjusted easily to his new world of sound.

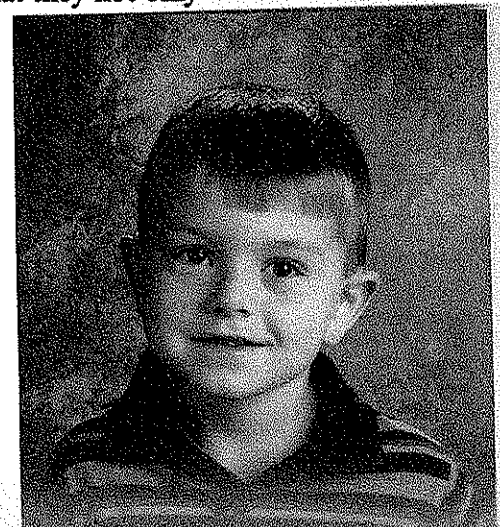
It is hard enough to take my son to a hearing test worrying if his hearing is getting worse, but even harder to imagine that if it is he may require a new technical device that I can't afford to buy. As a parent, it is heart aching to be faced with these financial worries along with the stresses of raising a child with a special need.

I don't believe taxpayers would want to pay hundreds of thousands of dollars to educate a child that would need little intervention with the use of hearing aids. My son is now enrolled in 5K and is receiving an exemplary education with normal hearing children. I see the gap between Dylan and his hearing peers closing more and more. Dylan is able to receive the education he not only deserves, but also is entitled to because of his hearing aids. And don't we all tell our children that education is the backbone of everything?

Our expectations for him are no lower than they are for his normal hearing siblings. We do not now nor will we ever accept or expect any less of him. He will be given the same opportunities and advantages in life and will be a contributing member to society. All because of hearing aids.

I am asking you today to support SB27 and AB16. This bill will not only help my son Dylan but the nearly 200 children born each year in the state of Wisconsin who are either deaf or hearing impaired. Hearing should not be a privilege but the right of all children. This is not about politics, but about our children and their future that they not only deserve but they are entitled to receive.

Amy Boehler and Dylan, 5 years old



Statement to the Assembly/ Senate Public Hearing for Hearing Aid Bills #27/#16

I come before you as the grandmother of Dylan, who has a genetic Bilateral Hearing Loss. His story is like many others in this room. The insurance company paid for the testing of his hearing, but upon diagnosis of hearing loss his parents were told that the insurance would not pay for hearing aids.

Dylan's parents qualified for help from the HIKE Fund to get his hearing aids, but presently the HIKE Fund is no longer even taking applications, because they cannot raise enough money to fill the needs of the many applicants. This leaves audiologists spending too much of their time away from families to searching for resources for hearing aids for their children.

Dylan's communication skills and understanding have rapidly progressed since getting his hearing aids. He still needs extra speech intervention, but he is far ahead of where he would be without the hearing aids. Had he gotten them earlier than 3 ½ years old he would have been even further ahead.

When babysitting for him one night, he began talking about the heart and being a nurse I decided this was a "teaching moment". We looked at a children's website, which showed how the heart works, where it is located in the chest and how it pumps. Then he and I compared the veins on our hands and arms, so he could visualize what he was seeing on the website.

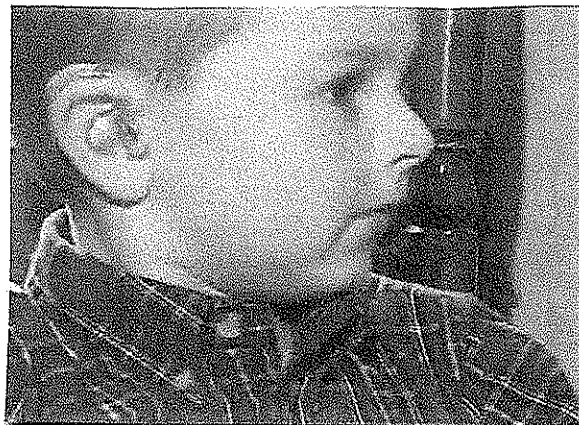
But Dylan's knowledge of the heart became very real on December 2<sup>nd</sup> of last year. His "Opa" died of a sudden heart attack. When his daddy told him that Opa had died of a heart attack, Dylan said, I know where the heart is and he pointed to his chest" and then in his sweet caring way he said, "Opa's spirit is in my heart always" as he pointed to his heart. If Dylan was not able to hear and to comprehend things like "the heart" he would never understand why "Opa" had left him. They were buddies and Dylan communicates his feelings of his loss very profoundly and quite often.

You will realize that the statements being made to this Committee may be different, but a similar theme echoes throughout this room--Early intervention influences language and vocabulary development. Scientific studies have proven it and families recognize it daily as their "now hearing child" interacts in a hearing world, if they are able to receive hearing aids. (See Benefits of Early Intervention For Children With Hearing Loss)

I ask that you listen carefully to the information and life stories being presented today and vote to move the Hearing Aid/Cochlear Implant Bills 27/16 requiring health insurance coverage of hearing and cochlear implants for persons under 18 years of age out of these committees to the floor for a vote.

Thank you,

Judy Wagner, R.N.  
609E Eastwyn Bay  
rwagner12@wi.rr.com



## SWEET SOUNDS TO MY EAR

Julie Spangler  
Janesville, WI



It is a pleasure not only to be here today, but to be able to **hear** the families come before you to testify. A year ago you may recall Representative Mike Sheridan sharing a story about one of his union sisters, that story was about me; here I am one year later to tell you how much I have benefited from my Cochlear Implant.

My parents couldn't understand why I didn't talk much when I was a little girl, it wasn't until I was enrolled in school, that I was diagnosed with a hearing loss, the Doctors believe I was born with congenital total deafness in my left ear, and partial deafness in my right ear. Not like today's technologies, they now can detect deafness from as young as a few days old. At the age of 6 years old I was fitted with my first hearing aid. My parents were initially told that due to my hearing loss, I could potentially lag years behind my classmates. However, I overcame the odds, performing competitively in school. I graduated 3rd in my senior class. I took on leadership roles early in life, something I have continued to do, until my recent total loss of hearing. I attended University of Southern Colorado for a year after I graduated from high school, and later got married and moved to Janesville from Colorado and had two beautiful children.

Until 5 years ago, I have adapted to this condition fairly well with the combination of my hearing aid and lip-reading. However, my hearing progressively was deteriorating. On January 13<sup>th</sup> 2007, I experienced a significant hearing loss in my right ear (the ear with the hearing aid). I awakened one morning to what would be my worst nightmare in life, and couldn't hear normal sounds at all. I took immediate action, and arranged to see my audiologist that day to which I had to have my husband call for me since I could not longer hear on the telephone. My doctor indicated that he didn't notice any particular damage or pathology in my ears. He said, "If the

hearing doesn't return in a few days, call UW-Madison and arrange to see the specialist." After a few days, some hearing returned, but not approximating what I had prior to this catastrophic loss. This hearing loss with some return of partial hearing recurred on several occasions. After the latest recurrence, my hearing never came back at all, so I arranged for my Dr.'s nurse to call the specialist at UW to make the appointment, since I no longer could hear well enough to use the telephone.

I finally saw the specialist on April 02, 2007, one day before my 42nd birthday. I had to wait 2 and a half months for an appointment with him, despite being advised by my sister (an Internal Medicine Specialist in California ) and her ENT physician colleague, that any delay in rapid diagnosis and treatment could result in permanent hearing loss. After examining me, the specialist stated that I was a perfect candidate for Cochlear Implant, which would be the appropriate treatment for me. My only down fall was, my present insurance didn't cover Cochlear Implants. Next was months of filing appeals with my insurance which later gotten denied, not once but twice. The cost of the implant was near around \$70,000!! I contacted my benefit representative that if the other insurances through my work place covered Implants. He said he knew one of the other didn't cover and possibly the third one may cover it. So he sent a letter to the insurance to see if it was a covered benefit. Two weeks later I was notified that it is a covered benefit. At his time it has been 6 months.

It has affected my life adversely in many ways, and has resulted in the most difficult six months of my life. Consequently, I have become very depressed. I could no longer communicate either by phone, or in person. I can try to lip-read, but this doesn't work effectively with everyone I encounter. I had come to the point where I would try to avoid people because I want to save myself frustration of ineffectively trying to communicate, over and over again, that I can't hear. I have overcome many obstacles in my life, despite being hearing impaired, and have been a motivator to many people. Previously, partial deafness has not kept me from doing what I am effective at doing (and hence, enjoy). My condition, however, had gotten so bad, that I couldn't communicate at all! I don't like to depend on other people to communicate for me. I lost my independence. Imagine, every time you hear your phone ring, recall that I could no longer hear or answer mine. Every time I need to make an appointment or handle matters normally requiring verbal communication, I had to rely on husband, children or friends to do it for me. There have been many days when I just withdraw and cry. I couldn't even go to a movie or listen to music anymore. Loosing my remaining hearing had taken a lot of things away from me. I am overwhelmed because the specialist said that I don't have to be disabled like this. I know these problems be mitigated to a considerable extent, if I were to have a Cochlear Implant done.

On December 11th I received my cochlear implant. I had to wait 6 weeks before the processor could be turned on, been over a year since this all began. I was given a sentence test, without looking at the audiologist's mouth. I had

gotten a hundred percent! I looked at my daughter, she started to cry, I cried!!! Tears of joy were over whelming. I was told as time goes by it would get better.

Life has been so great for me. Better then ever. Everyone sounds more normal. There would be times I would just sit and close my eyes and listen to the sounds around me. I heard my 4 month old twin niece and nephew cry for the first time. I never take anything for granted. I thank god for everyday he has given me.

I have gotten my life back once again. Now I continue to where I left off helping out my community organizations. Last fall I went back to college after 24 years to complete my college degree in Human Services and Speech Communication. I have also become Trustee through my union, Co-Chair of my UAW Community Service and volunteering for Hospice, Enhancing the Quality of Life to the End of Life. Not only has the implant has given me quality of life for me, but others I service. Also I can hear on the phone once again, actually better then ever.

I am living proof that hearing aids and cochlear implants has given me quality of life. Children are our greatest resources; they learn better when they are young. They have dreams like everyone else, with the help of aids and implants, it will help them improve the quality of their life and will be easier for them to pursue their dreams.

I have even taken the time to do research. Providing hearing aids and cochlear implants to children has endless benefits, and there is a great deal of research that provides evidence of these benefits. One notable research article is by Christine Yoshinaga-Itano et al. (1998), "Language of Early- and Later-Identified Children with Hearing Loss". This article summarizes the differences in language development between children who were identified with hearing loss prior to six months of age and who were fit with amplification (hearing aids or cochlear implants), and those who were identified after six months of age and received intervention in the form of amplification later. Essentially, the authors found that early identified children demonstrate significantly better receptive and expressive language that those identified later, and by the age of 5, hearing impaired children fit with amplification have average language scores within the normal range of children with normal hearing.

I hope my voice will be heard for those who can't hear. Please support this bill; it will make a difference a child's life!!! Give them the quality of life they deserve!!!

Julie Spangler  
2304 Rutledge Ave  
Janesville, WI 53545

Bradley Sipla was born on February 4, 2000 by emergency c-section. His umbilical cord had a knot in it and was wrapped around his neck. He went without oxygen for approximately 8 to 9 minutes and he had an apgar score of 0 at birth. Bradley spent approximately 1 week in the NICU where he was diagnosed with deafness in his left ear and hearing loss in his right. However, prior to leaving the hospital it was determined he was not deaf in his left ear but rather he had profound hearing loss in that ear.

Further hearing tests were done and at approximately 6 to 9 months of age Bradley got his first behind the ear hearing aid in his left ear. Tests determined that he did not need an aid in his right ear. Bradley repeatedly removed his hearing aid and eventually the audiologist said they were wrong about their initial diagnosis and he did not need hearing aids at all. If the aid had been kept insurance would not have paid for it.

Bradley spent the next 5 ½ years with an undiagnosed hearing loss. He was taken for regular audiology appointments due to his history but the audiologists always found it difficult to test him and thus the test results were inaccurate. When Bradley was 6 years old the audiology department decided to try using 2 audiologists with him. It was at that time that he was finally accurately diagnosed with hearing loss in both ears. Bradley was found to have sensorineural hearing loss, which is a hearing loss that occurs in the inner ear, the auditory nerve or in the brain. This type of hearing loss is not progressive but it can never get better because the nerve cells cannot grow back or be replaced. Bradley's hearing loss is the result of his severe lack of oxygen at birth. He has had other complications from that lack of oxygen as well.

On March 15, 2006 Bradley came home with his brand new behind the ear hearing aids. On the ride home he asked what the noise was that he was hearing. He was hearing road noise for the very first time at age 6. From that day forward he has loved his hearing aids and almost never goes without them. At such a young age he recognizes his great need for them.

Bradley's behind the ear hearing aids cost \$1000.00 per ear. This was the cost in 2006, we have been told when he is ready for new hearing aids (as they wear out every 3 to 5 years) the price will be around \$1800.00 per ear. We had excellent top of the line insurance at the time of his diagnosis and we thought the audiologist was wrong when she told us it was likely our insurance would not pay for his hearing aids. On the ride home from ordering the hearing aids we called the insurance company and we were indeed told they would not pay anything toward the cost of the hearing aids. We paid for Bradley's hearing aids completely out of our own pockets.

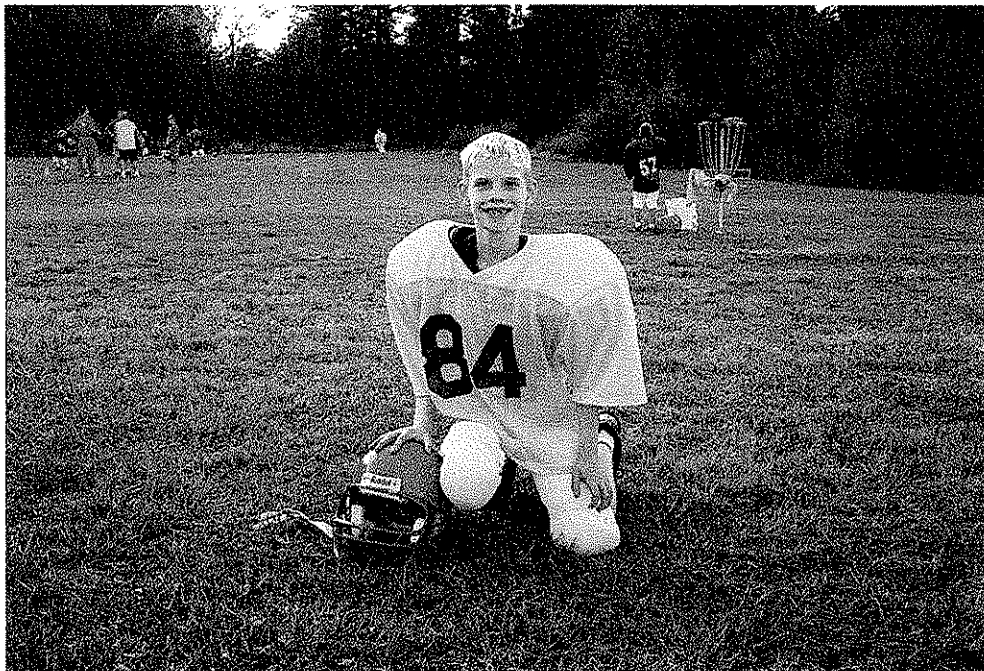
Bradley is an example of what can happen to a child that does not have hearing aids if he needs them. Bradley spoke much later than most children and his speech is still delayed. This is very common in children who have hearing loss because hearing is directly tied to speech development. He also sat up late, crawled late, walked late and potty trained very late. He was all around a delayed child mainly because he was missing so much from not hearing. He did have Birth to 3 and Early Childhood services but because of the undiagnosed hearing loss those services couldn't do what they were intended to do. It is

extremely difficult to feel a part of the world that surrounds you when you don't understand the language. When other children were talking (or signing in some cases) Bradley was not and he would often hit others in frustration because he couldn't communicate with them. Not only couldn't he talk, he didn't have words for most things around him. To this day he struggles with naming objects and things in his world because he spent those incredibly important developmental years hearing muffled voices and sounds. He had to repeat kindergarten because he couldn't write his name or read like the other children. He still struggles in school but he has made great leaps and bounds since getting fitted for hearing aids.

Hearing aids are not cosmetic nor are they a choice. For a person who is hard of hearing they are a necessity to live. Bradley is a living example of this. He lived for many years without hearing aids and this has had a negative impact on his life. We should never say what if, but when we wrote this testimony it was a little hard not to think of how Bradley might be different if he was diagnosed right away and had his hearing aids his whole life. Please stop insurance companies from denying this basic medical necessity to our children by passing Senate Bill 27, Assembly Bill 16.

Thank you.

*Scott & Tracy Sipla*  
Scott & Tracy Sipla  
1430 11<sup>th</sup> Avenue  
Friendship, WI 53934  
(608) 564-7571  
[ssipla@hotmail.com](mailto:ssipla@hotmail.com)



Bradley Sipla



# Penny Bernard Schaber

*Serving the heart of Appleton*

STATE REPRESENTATIVE 57th ASSEMBLY DISTRICT

*March 17, 2009*

## Letter in Support of the Cochlear Implant Bill

I am not able to appear before the committee this morning due to a pre-scheduled Informational Hearing for the Health and Health Care Reform Committee.

As a School Based physical therapist who has seen the very positive impacts of the cochlear implant on students, I want to present my full support for this bill.

The true impact of this bill on a child with a hearing deficit can not be clearly known by those of us who can hear. I have observed children in school before and after the device is implanted. The joy and excitement on the face of a child who is able to hear because of these devices is indescribable.

Also as a School Based physical therapist I know that the fiscal impact of this bill for the school districts can be very positive. It will allow the school districts to limit the amount of one to one and interpreter assistance that a child needs in school due to a hearing loss. This will save school districts and the state money used to pay for these services.

For these reasons, I would like to submit my full report for this bill.

Respectfully,

*Penny Bernard Schaber*



I would like you to consider supporting this recent attempt to pass a bill concerning the coverage of hearing aids for children. I have been teaching deaf and hard of hearing children for more than 30 years. Language competence is the key to these children being able to be successful in life. I have seen many changes in this field over the years, but one constant has been that early amplification for children with hearing loss is critical for establishing language.

Several years ago a critical piece in assisting with this was established. Universal Newborn Hearing Screening, where hospitals screen newborn infants for possible hearing loss, has revealed many hearing losses early where in the past they might not be discovered until the child was two or three. After identification, it is critical to provide the child with amplification so that speech and sound are available in order to develop language in a normal way. This amplification piece is a difficult one for most parents to afford. When I first started working one could purchase a set of hearing aids for roughly \$600. Now the price is usually \$6000. Families are already devastated by the knowledge that their child has a hearing loss and then to add financial responsibilities onto it is crippling.

There are private organizations that do help with this, but most of them do not offer their service until the family has filled out their paperwork and the paperwork has gone through a number of committees (rightly so). By the time that families are approved, the child has lost a great deal of time without amplification. Most families are not willing to wait that long.

Another option for families is to go on Medical Assistance. Medical Assistance will pay for hearing aids. I remember working with at least one family where the parent took a less paying job in order to qualify for Medical Assistance so that the costs related to the hearing loss were paid for. This hardly seems right for several reasons. Why would the state force families to take a lower paying job in order to provide basic services for their children? Why are some children able to receive these services for no cost, while others are penalized?

I am sure that one of your concerns is that insurance companies already have high rates and this will raise them even further. I'm sure that may be true, but this is such a low incidence population, I cannot foresee this being a huge jump in already high prices. Most people who are not familiar with hearing loss are surprised that this is not covered by insurance.

Two years ago I attended a program in Pennsylvania where I was able to discuss the field of deaf education with other professionals from around the country. Most of the time I boast of the things that are happening in Wisconsin, but I could not sing the praises of early amplification in our state. Most states have some kind of way of getting young children amplification. I am not saying that we need to be like every other state, but I think that you too are proud of our state and would want to be aware where we are lagging.

Please consider supporting this legislation. Please do what you can to sustain it while it is in committee. If you would like more information, I would be glad to supply you with it. Thank you for your time.

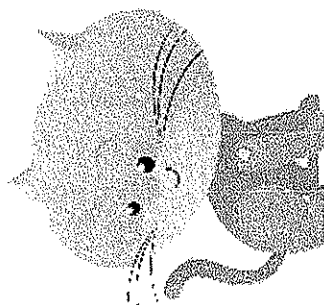
Mary Kahler

209 Beaver Street  
Beaver Dam, WI

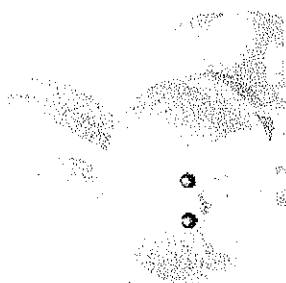
My Name is Anna I am a 7<sup>th</sup> grader with one hearing aid. I am Hard of hearing in both ear with a moderate to severe hearing loss. I am here to support the Senate Bill 27, Assembly Bill 16, that will allow children who are deaf and hard of hearing to get hearing aids or cochlear implants covered by insurance. This issue is very important to me because my hearing aid has changed my life. I have now had my hearing aid for half of my life. I got it when I was 6 which means I missed many sounds in my early days. Once I got it my brain needed to start realizing that there was more sound. My speech needed improving I worked hard in speech therapy for thirty minutes once a week for six years. Many of my friends who are hearing, hard of hearing, and deaf all mean so much to me. With my hearing aid I'm able to communicate a lot better. I can still communicate with out my hearing aid but it helps so much. My family was lucky enough to be able to purchase my first hearing aid with out any insurance. By the time I needed my second hearing aid my mother's health insurance covered up to one thousand dollars of a hearing aid that cost twenty three hundred dollars. With the Economic troubles many families don't have thousands of dollars lying around their house. Knowing how much it has helped me I want other kids to hear sounds that want to have sound in their life.

Emily!

Cat!



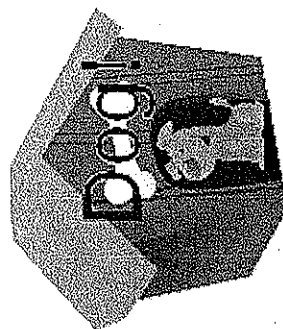
Rabbit!



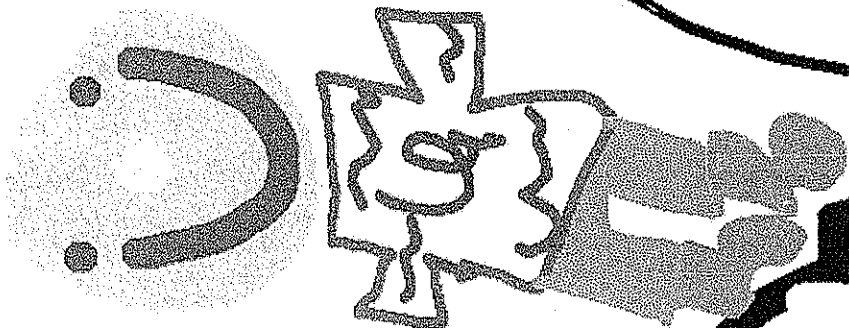
Mouse!



Dog!

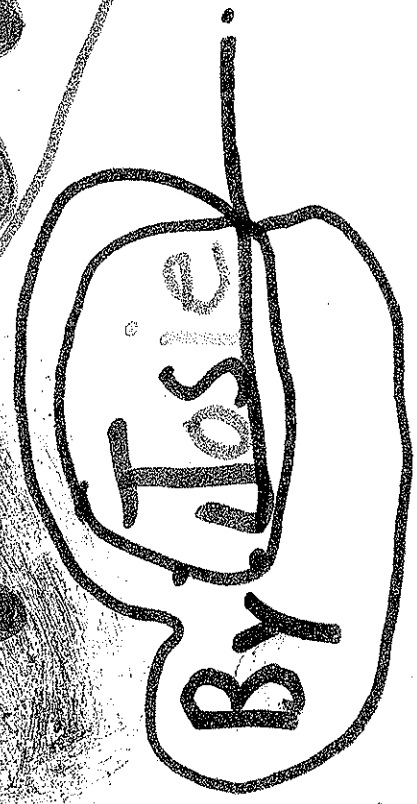
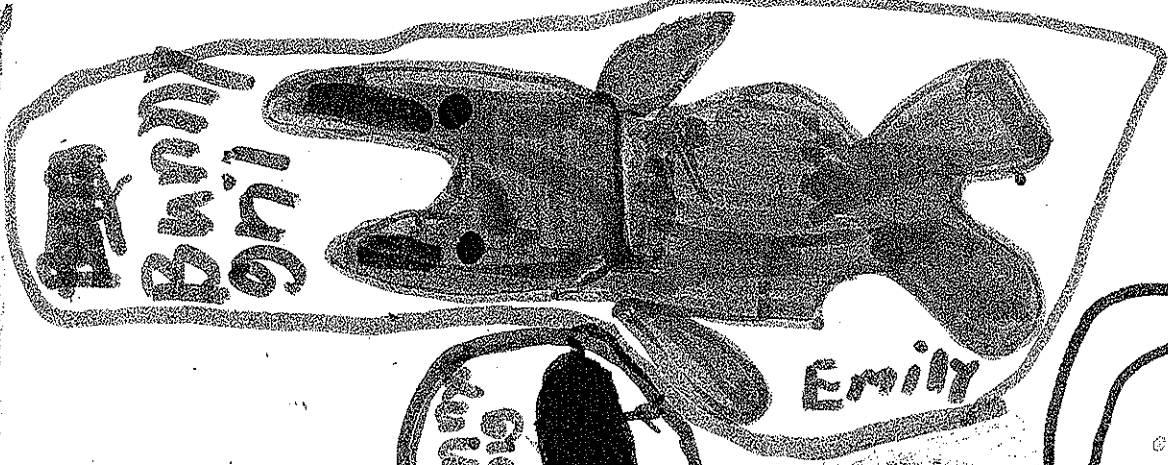


I want to own  
a pet store.



# I am going to be a vet.

Just pets



Hello Members of the Senate and Assembly

My name is Peyton Nelson and I am here to support Senate Bill 27 and Assembly Bill 16.

I am hard of hearing. I wear digital hearing aids in both of my ears. My hearing aids are **VERY** important to me. They help me understand what people are saying. They help me hear environmental sounds to keep me safe. They help me to understand conversations with my peers. I have a lot of friends, so my hearing aids help me to know what is going on at my school. I also use an FM system at school which helps me hear my teachers better as classrooms are very loud and it is difficult for me to learn with all the noise. If I did not have my hearing aids or FM, I would not be able to understand very much! That would be very frustrating.

I hope that you will pass this Bill so that ALL kids with hearing loss like me can get hearing aids and that their Moms and Dads don't have to pay for them. That's why I am here, because this is very important.

Hearing aids are very expensive. Moms and Dads should not have to pay for them - insurance companies should!

Thank you!

*Peyton Nelson*

## **Testimony in favor of passing Senate Bill 27 and Assembly Bill 16**

Presented by: Michael and Elaine Flood  
300 Wentworth Lane  
Appleton, WI 54913  
Email: floodmi@msn.com

Parents of seven year-old Tommy Flood: hard of hearing (requires two hearing aids)  
First Grader at Ferber Elementary in Appleton

### **Reasons to pass SB 27 and AB 16**

- The method of operation of the insurance industry has always been to spread the expense of a rare, known risk from a small number of people to many people. In this way, everyone pays a manageable amount so no one person pays a huge amount.
- Approximately 100 babies are born deaf or hard of hearing in Wisconsin each year. There are approximately 200 children identified as deaf or hard of hearing in Wisconsin each year. Approximately 71,000 babies are born in Wisconsin each year based on CDC statistics. Thus, approximately 0.35% of children will be identified as deaf or hard of hearing in Wisconsin each year: a relatively rare and known risk.
- Based on the insurance industry's own historical method of operation, covering the expense of hearing aids/cochlear implants for children is a completely consistent and logical request.
- It is in keeping with the growing bipartisan national talk of focusing more of our limited healthcare resources/insurance dollars on "preventative care". Several states have laws requiring insurance coverage for deaf or hard of hearing children.

Kelly Hilliker  
3816 Martin Lane  
Two Rivers, WI 54241  
920-793-4812  
Married and father of 3 children, one who is hard of hearing

I am in full support of Senate Bill 27/Assembly Bill 16.

Like most people, I was very ignorant of the deaf culture until 4 ½ years ago. At that time, our third child was born and the newborn screening hearing test determined she had a hearing loss. Subsequent testing determined she had a bilateral moderate to severe hearing loss. All three pediatric audiologists we met with recommended hearing aids for both ears as soon as possible. Each told us that each day that passed without the use of hearing aids was equivalent to one week lost of learned speech, which ultimately would prolong the needed speech therapy she would eventually receive. This beautiful child was our little miracle. We named her Emjay Marie. She came nearly 2 years after my wife had been diagnosed with cancer and we had been told that we would not be able to have any more children because of the necessary cancer treatments. Learning of her permanent hearing loss was devastating, confusing and frustrating.

The company I work for, a large state electric utility, just began offering insurance for hearing aids at the time of her diagnosis. We learned that the cost of the hearing aids were going to be \$3,000, and that insurance would cover up to \$1,500. When I asked why there was a limit and not a percentage covered, I was told that insurance companies feel hearing aids are a cosmetic fix. I was both stunned and appalled. I was still trying to accept the fact my daughter was hard of hearing and may be deaf one day, and the hearing culture was looking at this situation as cosmetic. The hearing aids were imperative to the acquisition of speech and I was being told they wouldn't pay for them because they were a beauty enhancer! Six weeks following the arrival of Emjay and the news of her hearing loss, my wife was diagnosed with breast cancer for the second time. Her treatments required chemotherapy, a double mastectomy, a complete hysterectomy and reconstructive surgery. That, on top of the burden of the necessary hearing aid purchase that could not be delayed, became a huge financial burden that took us four years to pay off.

Emjay received her first set of hearing aids at 3 months of age. It was a struggle at times to get her to keep them in her ears, but I can vividly remember the day she took them out and then realized the hearing world she had just experienced was gone. From that day forward, her "Ears", as we affectionately call them, are the first thing she asks for in the morning and the last thing we take care of before hitting the pillow at night. She is lost, frustrated and often times, frightened without them.



## Ashley Ann Petrina

Hello, my name is Carol Petrina, and my daughter Ashley is profoundly deaf in both ears. Her hearing loss was identified through the Newborn Hearing Screening at birth. My family has a history of hearing loss. I have one niece and two nephews who also have hearing loss. I witnessed the difficulties hearing loss brought to my brothers' children. My niece who is now in her late 20's did not have the opportunities our children of today have. Cochlear implants were then considered very experimental and too expensive to obtain. She received little benefit from hearing aids. My niece uses ASL, but since most of the hearing members of my family do not know sign language, she cannot communicate well with her own family. At times, she feels very alone.

Fortunately for my daughter, the advances in cochlear implant technology have opened new doors for a deaf child. Ashley received her first implant at 14 months and her second at 19 months. We are very fortunate that our insurance, after diligent persistence on our part, did cover her cochlear implant surgeries. Ashley will be turning three in two weeks and beginning mainstream preschool. Ashley has made tremendous gains in her speech and language and is, in fact, performing above her age level. Most importantly, she is a bright little girl who is accessing all the sounds around her. She is singing songs, and she can hear if Mom says "I love you" or she can hear if a car horn is honking to warn her of danger. Her life without her implants would be very different. As a mother, I cannot imagine what it would be like to need cochlear implants or hearing aids and not be able to get them for my child. I am here today to support Senate Bill 27 and Assembly Bill 16 so that no parent would have to face this heartbreaking situation.

*Carol Petrina  
N3736 Birchwood Rd.  
Kenosha, WI 53146  
920-388-4038*



Hello, my name is Jenny Geiken and I am the Executive Director and Founder of Hand-N-Hand of Northeastern Wisconsin, Inc., a non-profit organization that provides support and resources to families who have children experiencing hearing loss. I also am a Birth to Three Consultant for infants and toddlers with hearing loss and a certified teacher of the Deaf and Hard of Hearing. As an educator in Wisconsin, I support Senate Bill 27, Assembly Bill 16, a bill that will allow children who are deaf and hard of hearing to obtain hearing aids and cochlear implants covered by insurance.

Universal Newborn Hearing Screenings are occurring in 99.5% of the hospitals in the state, children are being identified with hearing loss at a much younger age than in the past. Every day in the United States, approximately 1 in 1,000 newborns (or 33 babies every day) is born profoundly deaf with another 2-3 out of 1,000 babies born with partial hearing loss, making hearing loss the number one birth defect in America. In 2007, in Wisconsin, 95 newborn babies were identified as having hearing loss through this testing.

Protocol for the UNHS is to screen hearing at birth, diagnose hearing failure, confirm hearing loss and receive intervention by 6 months of age. Following the diagnosis of hearing loss, parents generally experience a range of feelings; not to mention the many decisions they are left to face in regards to choices of communication modality and amplification. Only to find out that once they have finally made a difficult decision of a hearing aid or cochlear implant, they now need to face the costs that lie ahead. These costs are incurred due to doctor visits, audiological testing, medical scans for surgery costs, surgery, and follow-up visits for ensuring proper fit of the devices. Next they face the "treatment" (therapy and specialists') costs that accompany the diagnosis/intervention related to hearing loss in effort to maximize hearing, speech and language levels. Families learn to work through these phases but the state of Wisconsin must give parents the assurance and support that the choices they make will not provide a hardship economically.

In the educational system, we as educators need to consider the factors that support educational needs of children with hearing impairment. Hearing impairment, including deafness, means significant impairment in hearing, with or without amplification, whether permanent or fluctuating that significantly adversely affects a child's educational performance including academic performance, speech perception and production or language and communication skills. When children are not identified and do not receive early intervention, special education for a child with hearing loss costs schools an additional \$420,000, and has a lifetime cost of approximately \$1 million per individual.\*

In effort to reduce educational costs consider the research:

- The sooner babies get assistance, the better their chances of developing language, normal communication skills, and leading productive lives.
- Infants identified with hearing loss can be fit with amplification by as young as 4 weeks of age; cochlear implants as early as 6 months. With appropriate early intervention, children with hearing loss can be mainstreamed in regular elementary and secondary education classrooms. Recent research has concluded that children born with a hearing loss who are identified and given appropriate intervention before 6 months of age demonstrated significantly better speech and reading comprehension than children identified after 6 months of age.\*
- Early detection of hearing loss followed with appropriate intervention minimizes the need for extensive habilitation during the school years and therefore reduces the burden on the IDEA Part B program.\*

A child's greatest resource is their family. Support Senate Bill 27 and give families the opportunity to choose hearing aids or cochlear implants without the fear of potential economic hardships.

Thank you for your time and please vote "yes" in support of Senate Bill 27.

\*Hearing Loss Association of America

*Jenny Geiken 2950 Yonder Ct. Green Bay WI 54313 (920)434-6226 jlgeiken@earthlink.net*

## Carol Burns – Speaking in favor of SB27 and AB16

Good morning and thank you for the opportunity to share my reasons for supporting SB27 and AB16 that are before you today.

I am here representing Hearing Loss Association of America-WI (HLAA-WI). We strongly support the bills before you. I am also here as an individual who grew up with severe to profound progressive hearing loss. My hearing loss was identified at age 5. It was a moderate to moderate-severe hearing loss. Like the parents you are hearing from today, my parents struggled to provide me with hearing aids as a child. I grew up in an era where educational services for disabled children in public schools were unheard of. We were relegated off to special schools. I would have been in a class of 10 year olds with a spectrum of disabilities as a first grader. Fortunately I was spared that fate – my parents petitioned our school district to accept me, which they did. However I struggled in the mainstream setting with no support services.

I still remember the day I received my first hearing aid, hearing the engine of our family car for the first time in my life. Imagine what other sounds important to my development that I was not hearing. I am most fortunate that my parents provided me with hearing aids – often stronger aids every 9 months as my loss rapidly progressed during grade school. This represented huge sacrifices on their part.

I also recall my concern when my hearing aid would break, or when the progression of my hearing loss was such that the current hearing aid was no longer working well. Informing my parents of this as an 8 year old was hard, because even at that young age I sensed that this meant slim financial resources were directed to ME and impacted my family's other needs. **No child should ever be in a situation where he/she might feel this kind of burden!**

As a young adult I attended college – carrying around a suitcase sized tape recorder (the old two wheel style) in order to have someone listen and mentor me after lecture classes that I could not hear. The stress of trying to keep up overwhelmed me and I eventually dropped out of college.

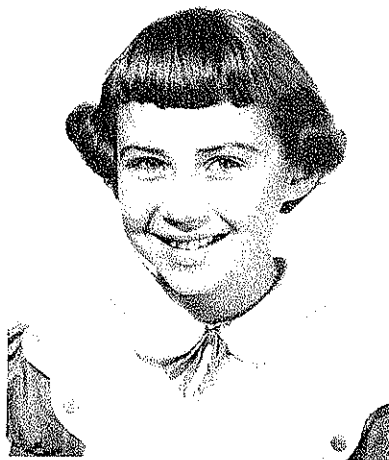
In my early 40's I began employment with the State of WI and enjoyed a successful career there – but I was still limited in how far I could progress because of my inability to use the phone. Then, in my early 50's my hearing took another downward spiral. I suffered from severe depression and experienced a high level of anxiety concerning my ability to successfully remain in the workplace. In the late 80's I had begun to research cochlear implant technology that I heard might help restore my hearing. Imagine my dismay when in 1996 I learned my state of WI employee benefits had a specific EXCLUSION for this surgical intervention which would enable me to remain employed! Worse, if one of my fellow employees was the parent of a child born deaf and wanted to provide his/her child with the OPTION of hearing, this was denied them as well. Prior to 1994 hearing aids were covered benefits, however that year they ceased to be a covered benefit. They were taken out of the plan to help fund significantly reduced co-payments for prescription drugs introduced that year. In 1996, part of the qualification process for a Cochlear Implant is testing in the BEST AIDED CONDITION. **This required the purchase of 2 hearing aids that were not covered by insurance simply to qualify to become a cochlear implant candidate!**

The unfortunate truth is that our children NEVER catch up when they do not receive appropriate intervention. Studies show children who do not learn oral communication as their first language (where manual communication is their first native language), have language deficits that substantially limit them in the workplace as adults. Studies show the overall cost to society when a child is born pre-lingually deaf is over a **MILLION DOLLARS**.

I urge you to pass these bills because they are simply Good Public Policy.

Thank you for your time!

Carol Burns



ALPINE  
SCHOOL DAYS 54.55

If you look close you can see the cord to my body worn Hearing Aid on the left side of the picture. We adults were once children like those you are hearing from today!

I would like to start by saying thank you-

You all hold the power to change my family's life forever and for that you are so privileged.

Finding out your child has hearing loss and is going deaf is about the most heart breaking moment in a parent's life. You go through all the stages of grief and guilt. I cried for days and felt like I did not know where to turn. I did research and looked for doctors or specialists, anything I could do to find someone who can fix this for my child.

However, nothing is worse than the day I called my insurance company, to find out where I can go to see a doctor or what kind of coverage we were going to get for our daughter and then they drop the bomb: hearing is not medically necessary..... I was in a state of shock and panic. I did not think those words could even be in the same sentence. As the tears roll down my face I realized as bad as I thought this was it was going to get worse. Not only did our family need to grieve and help our daughter but with in the first month of finding out about our daughters condition we had a medical bill of \$30,000 just to diagnose what her condition was and we still had not purchased any of the equipment she was going to need to live every day.

Our daughter has a condition called Enlarged Vestibular Aqueducts and she is going to lose all of her hearing. In the past year she has lost all of her hearing in her left ear and has a moderate loss in her right ear. Her needs seem to change every 6 months. Just when you think you bought the equipment she needed like an FM system so she can function in school or participate in sports we find out she lost more hearing and now she needs a new hearing aid and a different kind of FM another 4,000.

No parent wants to tell their child sorry you can't hear the cars when you cross the street or a car driving by. No more riding your bike because you can't hear the cars passing by and I don't want her to be hit by a car. From listening to music or playing the piano she has given up almost every extracurricular activity she used to participate in because of a fear of leaving the house since she can't hear in the different environments. Our daughter begs for help and wants someone to just fix it and how do you tell her you can't afford to buy more equipment.

We have been trying to get a Cochlear Implant for our daughter but our insurance will not pay for it. In the mean time she struggles in school and her speech is delayed. This does not even mention the social impact on her. She feels neglected and frustrated she doesn't understand why no one is helping her. Watching your child be left out of social conversations with other kids and physically seeing her self esteem drop is excruciating. She sits at the lunch table in school and doesn't talk with anyone because she can't hear the person sitting next to her. It breaks my heart when she says Mom's and Dad's and Doctors are supposed to help kids and no one is helping me. I cannot find it within me to tell her we can't afford it hopefully something will change and then you will be able to hear.

I beg of your help today please help our daughter in a time where it seems like no one else is. Thank you for your time and consideration.

Good morning (afternoon)

My name is Alana and I am 6 and  $\frac{3}{4}$  and I have hearing loss. I use a FM system at school and I am trying a hearing aid right now. Without my FM system at school I would not hear my teacher. My FM system cost three thousand dollars and I try to take very good care of it. I have lost more hearing so I am trying a hearing aid right now but it would cost my Mom and Dad a lot of money to buy me one and they would have to make my FM system work with my aid which is more money. My Mom said that would be over four thousand dollars. I am deaf in my left ear and my parents and my doctor keep talking about a cochlear implant and if I can get one but right now my insurance will not pay for it and my parents do not have enough money. I know it costs a lot but it would be really cool to hear in my left ear.

I wish insurance companies would pay for this so my Mom and Dad would not have to because the stuff I use to help me hear every day is very important to me. I really need to have these things so that I can hear every day. They keep me safe so I can hear cars when they drive by or when I am on my bike my Mom can tell me when a car is coming. They also help me hear so I can play soccer or basketball and then I can still hear the coach. If this bill is passed maybe I will get to hear in my left ear.

Lots of my friends have glasses or use a walker or a wheel chair to help them and the insurance pays for that but not my aids. If this happens I might get to keep my hearing aid and maybe hear in my left ear that would be AWESOME!! I also hope you will change that so my Mom and Dad will have more money to spend on me!!

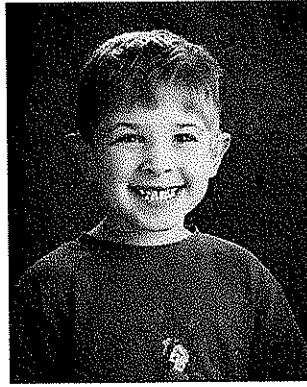
Thank You

From: "Happel's" <ctaj@charter.net>  
Subject: **try this...**  
Date: March 18, 2009 7:14:37 AM CDT  
To: <4bjs@charter.net>

My name is Andrea Happel and I am 12 years old. I live in La Crosse, WI. I have been hard of hearing since I was diagnosed with a mild to moderate hearing <sup>loss</sup> ~~lose~~ when I was 4. While I passed the new-born hearing screening my hearing just went away as I got older. We don't know what is causing my hearing loss; we do know that I need hearing aids. When the doctor told me that I needed hearing aids I was excited. When I got them they were better than I dreamed. I didn't say "what" as much, and in school I didn't need the teacher to repeat directions. Even though the hearing aids were awesome, they cost so much money. We got a loan from the clinic to pay for them. When I first got my hearing aids, I could hear my hair move – did you know your hair makes sound when it moves? I didn't – until I got my hearing aids. Also at first, flushing the toilet made me jump because it made a loud sound! But now I know that my hearing aids do so much more for me like I can hear clearer, the teacher doesn't have to repeat things for me, I can answer my parents on their first call (I can choose to "selective listen!"). My hearing aids also make me more interesting - I get the opportunity to teach people about hearing and how hearing works, I also get to teach people that just because we have hearing aids doesn't mean we need help – we're just as smart as or good as anyone without hearing aids. I think everyone who has hearing loss should have the same opportunities as me. Hearing should be something everyone can choose to have – regardless of how much money you do or don't have. This is why Senate Bill 27 and Assembly Bill 16 needs to pass.

Thank you for listening.

***Henry Severson, age 6, has a profound hearing loss and wears bilateral hearing aids.***



**We live in a hearing society. Being able to hear is not a luxury. Please support insurance coverage for hearing aids and cochlear implants for children under age 18. Please support SB 27 and AB 16.**

- The Severson Family, Beth, Sean, Henry (6), and Nora (3), lives in Madison, Wisconsin.
- Henry's mom, Beth, is a speech and language pathologist and knows that hearing is critical for articulation, language, and literacy development.
- Henry was a typically developing child until speech and hearing concerns caused his parents to have his hearing tested at age 3. He was diagnosed with a profound hearing loss. Profound means that Henry is legally deaf. Unaided, a chainsaw at close range sounds like a whisper to him. The cause is still unknown.
- The family's insurance company denied their claim and did not cover the cost of Henry's hearing aids. The Seversons felt the financial burden of having to pay over \$5000 so that their son could hear.
- These are some of the things Henry **can** do because he wears hearing aids to increase his hearing ability:
  - Henry improved his speech intelligibility from 20% to over 90%. He no longer has a speech/language disability. Hearing aids help Henry have intelligible speech.
  - Henry can communicate effectively and independently with hearing people. He has made many friends and enjoys playing with them outside of school. Without his aids, Henry would not be able to communicate well with his friends in the neighborhood or at school.
  - Henry is reading at a *second grade level in kindergarten*. He can recite all 44 presidents! His ability to read is largely due to the important auditory skill of hearing sounds in words and being able to manipulate those sounds using speech. He does not need alternative reading instruction, like visual phonics.
  - Henry can be independent at school. He uses an FM system (i.e., a system with a transmitter, receiver, and microphone) to better hear his teacher's voice and does not need an interpreter or assistant.
- Henry's early interventions (i.e., timely amplification with hearing aids and therapy) are **saving Madison taxpayers tens of thousands of dollars** each year. Henry does not need a sign language interpreter, special education assistant, speech/language therapy, or unconventional literacy instruction (e.g., visual phonics). He does not need to attend a special school. These things would cost the school district, and therefore taxpayers, thousands of dollars each year.
- We live in a hearing society. Being able to hear is not a luxury. We urge you to please support Senate Bill 27 and Assembly Bill 16.

**THANK YOU** from The Severson Family - 4255 Mohawk Drive - Madison, WI 53711 – (608)273-6011

March 18, 2009

To the Committee Members of the Joint Hearing on Senate Bill 27 and Assembly Bill 16,

I am a teacher of the Deaf and Hard of Hearing in Milwaukee Public Schools. I am attending this session with one of my students and her mother. I support the passing of Senate Bill 27 and Assembly Bill 16 and I strongly encourage you to vote for its passage. I am not here today to change my life or to make my life better or easier. I am here to help make the lives of my students and their families better and easier. Hearing aids and cochlear implants are not seen as a luxury to my students, as insurance companies obviously see them; to my students hearing aids are a necessity. They allow my students to play safely outside, learn how to discriminate the difference between a short i and a short e sound and allow them to learn about science and history. Parents should not have to make financial sacrifices to buy their child a hearing aid or cochlear implant when they are already burdened with the additional responsibilities that they face with having a child with a hearing loss, such as several trips a year to the audiologist's office to get equipment fixed, attending IEP meetings and yearly hearing tests. Since hearing loss is often hereditary, some families face additional financial hardships because they have more than one child needing hearing aids or cochlear implants such as the mother I have attended today's session with who has two daughter who need hearing aids.

As a teacher of the Deaf and Hard of Hearing I often share my knowledge and experience with parents of my students to help them make decisions that are in the best interest of their child, such as letting parents know that their child needs to wear their hearing aids all waking hours to easily acquire language and that their child needs a quiet environment to easily hear language. I don't have time to quote research studies or statistics to parents that support the information I am giving them, but the parents of my students know that I have the best interest of their child at heart and they trust the information I am giving them. I am asking the same of you. I could spend hours citing research studies and give you anecdotal tales of how hearing aids and cochlear implants have given my students the future they deserve, but there isn't time for that. I have spent 22 years of my life dedicated to helping individuals with hearing loss. I have taken the time to come here today to speak to the committee. I hope that you can trust me when I say that passing Senate Bill 27 and Assembly Bill 16 is not only in the best interest of our children and families, but it is in the best interest of the state of Wisconsin. Your passage of Senate Bill 27 and Assembly Bill 16 will send the message that Wisconsin cares about our children and our families. Passing these bills is the right thing to do. It is the necessary thing to do. It is the honorable thing to do and I have faith that the committee will see this and pass Senate Bill 27 and Assembly Bill 16 for the sake of our children. Thank you.

Sincerely,

Tina Staszewski  
Teacher of the Deaf and Hard of Hearing  
Neeskara Elementary School  
1601 N. Hawley Rd.  
Milwaukee, WI 53208  
(414)405-8033



Thank you for the opportunity to speak at this hearing today.

My name is Todd Blobe and this is my 8 year old son, Ryan. We are from the Appleton area.

Ryan was diagnosed with severe hearing loss at the age of 3. We don't know the cause. I remember how shocking and upsetting this news was for me and my wife. Ryan was too young to understand the meaning of "sensorineural hearing loss." I remember calling my insurance company and discovering that hearing aids were not covered under my health insurance policy. A double whammy in the same day. Virtually everyone with whom I have ever discussed this issue is literally shocked at this lack of coverage.

This past summer, Ryan was fitted with digital hearing aids at a cost of \$3300. The audiologists from the Appleton Public School System also recommended a \$2400 FM classroom amplification system for Ryan. Not a problem, right? Surely, the school system would provide that. What makes our case perhaps a little unique is the fact that Ryan attends a parochial grade school. The public school system does not provide funds for classroom amplification equipment in private schools. After doing a great deal of research, we were able to provide an alternate system utilizing new technology for \$1400. Total cost for new equipment this past summer--\$4700 (none of which was covered by insurance or the school system).

Thankfully, we were able to provide these things for Ryan. He does well with his hearing aids. I can't imagine trying to pay for all of this equipment on a tight budget.

As taxpayers who support the public schools, we would like to see less differentiation of audiology services provided

between public and private schools. We are, however, thankful for the services the Appleton School District does provide. They do a great job!

One topic that is often overlooked with hearing impaired kids is that of safety. These kids are missing a sense that Mother Nature intended to help keep them safe. Kids can do irrational things. A couple of summers ago, we were at a cottage and Ryan was playing with his cousins in the front yard. Lake water and electronics don't go well together so Ryan was not wearing his hearing aids. I knew sooner or later the ball the kids were playing with would go out into the road, so I was watching like a hawk. Sure enough, into the road went the ball, followed closely by Ryan. It was at that point I realized he wouldn't even hear an approaching car coming like other kids could.

Without amplification, hearing impaired kids can't hear the cracking of ice as they wander on a weak section of frozen pond. They can't hear the voices of the people on a toboggan as it hurtles down a hill at them. Parents cannot always be at arm's length from a child to pull them to safety. Sometimes a sound or a voice is the only difference between a near miss and serious harm. Ultimately, the insurance industry is likely to pay for these injuries when they occur. Perhaps they can save some money up front by providing coverage for hearing aids and cochlear implants.

Wisconsin is proactive by providing coverage under the state healthcare plan. Please continue to be proactive and join the 10 other states that require insurance coverage for children who are deaf or hard of hearing. For them, these devices are necessities, not merely options.

Thank you.

To: Senator Erpenbach, Chair, and Members of the Committee on Health, Health Insurance, Privacy, Property Tax Relief and Revenue  
Representative Cullen, Chair and Members of the Committee on Insurance  
From: Alicia Boehme, Disability Rights Wisconsin  
Subject: **Senate Bill 26 and Assembly Bill 16**

**Make a commitment to children who are deaf and hard of hearing in Wisconsin**

I am testifying today wearing two hats. First, I am a parent of a child who is hard of hearing. Oliver, my son, is 2 years old and has been diagnosed as having bilateral mild to moderate hearing loss. He uses hearing aids to develop language and speech as well as to interact socially.

I am also testifying as an employee of Disability Rights Wisconsin (DRW). DRW is the designated Protection and Advocacy organization for people with disabilities in Wisconsin.

Oliver was identified as having potential hearing loss upon discharge from the hospital when he was born. Since 2002, hospitals in Wisconsin screen newborns to identify potential hearing loss. The program has been extremely successful in identifying babies who may be deaf or hard of hearing and referring families for further testing. Identification, however, is half the battle. Intervention is the other half. **And the reality is that families in Wisconsin are having trouble paying for hearing aids and cochlear implants for their children.**

Currently, insurance companies are not required to cover any cost associated with hearing aids or cochlear implants for the children of our state. Approximately 200-300 babies are born each year in Wisconsin who are deaf or hard of hearing. According to a survey completed by the Wisconsin Chapter of Hands and Voices, the majority of insurance companies are not paying for the cost of hearing aids. Fifty-four percent (54%) of the parents surveyed did not have insurance that covered any of the cost for hearing aids for their children. The average out-of-pocket expense for these parents was \$4,100. Parents with partial coverage for hearing aids did not fair much better; their out of pocket expense averaged \$3,727.

It does not make sense to identify babies who are deaf and hard of hearing and not intervene. Research shows that when children do not receive early intervention, there are significant social and economic costs. Hearing loss impacts language and speech development, social interactions, academic achievement and employment prospects. According to researchers, early intervention can provide savings of between \$5,000 -

\$10,000 per child per year in reduced or eliminated special education services<sup>1</sup>. And over a lifetime, early intervention can reach a savings of about 1 million dollars per person<sup>2</sup>.

Families in Wisconsin are struggling to pay for interventions, and there is a true need for insurance coverage of hearing aids and cochlear implants. Here are just a few testimonials from families across the state<sup>3</sup>.

- “I knew I could not afford the \$4,000 for new hearing aids even with the \$1,000 being covered by insurance for the aids themselves...Since I have 2 deaf children, I really need to get outside support...”
- “We are still paying the credit that we had to borrow using our credit card company.”
- “I hate the thought of sacrificing what is best for my child because of money, and yet there may be no other option if insurance companies do not help cover these medical expenses.”

**For additional testimonials, see <http://www.LetKidsHear.org>, a website dedicated to passing hearing aid and cochlear implant legislation for children in Wisconsin.**

Here are some very important facts about SB27/AB16. When passed, the law will:

- 1) **Provide families with choice.** Keep in mind that not all families who are eligible will choose to implant their child or purchase hearing aids.
- 2) **Ensure that an additional 1/3<sup>rd</sup> plus of all children under the age of 18 in the state will have hearing aid and cochlear implant coverage.** If passed, this bill will require group and individual plans as well as the self-insured plans that are run by the state and other Wisconsin governmental entities. So, this bill closes a large gap. Children who are covered under the Medicaid plan already have hearing aid and cochlear implant coverage.  
One major group of insured individuals that are not covered under this plan and who may (or may not) already have coverage are those covered under self-insured plans (except for those run by the state or other governmental entities). The bill does not mandate coverage for self-insured plans because the state does not have the authority to impose a mandate on these plans. As an aside, some of these plans, such as our family's self-insurance plan already have some coverage for hearing aids and cochlear implants for children. Also, self-insured plans typically align themselves with the standard of care that this bill would set.
- 3) **Have a cost that is both consistent and minimal.** The number of children who are born each year that are deaf and hard of hearing is a relatively static number. It is not growing. Also, the bill limits the coverage of hearing aids to

<sup>1</sup> Yoshinago-Itano, Christie, and Gravel, Judith. The Evidence for Universal Newborn Hearing Screening. *American Journal of Audiology*, December 2001; 10: 62-64.

<sup>2</sup> These figures are based on 1993 numbers as reported by Johnson, J.L., Mauk, G.W., Takekawa, K.M., Simon, P.R., Sia, C.C.J., and Blackwell, P.M. Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Seminars in Hearing*. 1993; 14: 105-119.

<sup>3</sup> These testimonials were collected by the Wisconsin Chapter for Hands and Voices.

one every 3 years. Last session the Office of the Commissioner of Insurance estimated that the bill would cost about .08 cents per privately insured person per month. Understanding that this session's bill will cost more, mainly to cover children through age 18, even if this doubles the cost to .16 cents per person per month, the cost of this bill would rise to be only \$1.92 per member per year. **This is less than the cost of a small popcorn at the movie theater!** Because of the low cost, this bill is not likely to impact small business owners in a significant way.

- 4) Save the government money by decreasing the cost of special education and other county and state services.
- 5) Put the priority of hearing aids and cochlear implants for children for insurance companies on the same level as orthopedic surgeries, pacemakers, birthmark removal, testing meters for individuals with diabetes, and Viagra. The ear is a major organ and deserves to be included under the umbrella of health care coverage.
- 6) Thirteen other states including Minnesota require this coverage. Illinois is also currently looking into passing similar legislation.

*Disability Rights Wisconsin stands behind Wisconsin children who are deaf or hard of hearing and need this vital coverage.*

We are pleased to see such strong support from the Department of Health Services, the Department of Education, the Department of Human Services, and the Department of Transportation endorse the passage of SB27 and AB16.

**I ask you to pass this very important bill and ensure that all children who are deaf and hard of hearing in Wisconsin.**

Thank you for your consideration.



## **Testimony Supporting Senate Bill 27 and Assembly Bill 16 – March 18<sup>th</sup> 2009**

My daughter, Hannah, has Ushers Syndrome which is a genetic disorder that affects her hearing and eyesight (Retinitis Pigmentosa). Hannah is severely deaf in both ears and has approximately 45% peripheral vision. The prognosis for Hannah is unclear, but potentially she could become totally deaf and blind. In the future Hannah may need to have cochlear implants. Currently there is no known cure for her eyesight condition.

I support the change Senate Bill 27 and Assembly Bill 16 to allow children who are deaf and hard of hearing to get hearing aids and cochlear implants covered by insurance.

Hannah will be 16 years old this weekend and to most people is a normal teenager, but Hannah is not normal, Hannah is exceptional. Despite being deaf from an early age, Hannah has managed to excel in many areas of her life.

- She is a 4.0 GPA Junior student at Appleton North High School.
- She skipped second grade due to her academic ability and is a year younger than her peers at school.
- She is accomplished cellist who plays in the school orchestra, has performed as a soloist and qualified for State competitions.
- She is a competitive swimmer, who has swum at local, state, national and international levels for her YMCA club, High School and National (Great Britain) teams.
- She is an assistant coach for a local Special Olympics Swim Team.
- She is secretary of the HOSA and Joint Chair of KEY Club at Appleton North High School.
- She speaks French fluently.
- She has spoken publicly in numerous events including a presentation at the 2006 Wisconsin Young Scholar Project Fair on the physics of swimming.
- She loves to bow and gun hunt for deer and turkey.
- She is planning to attend college to study Medicine and is planning on being a surgeon.
- She will be applying to Princeton University in the fall, as well as UW Madison.
- She is also a big sister to her younger sister Rebecca.

So why is all this relevant?

We are very lucky that we have been able to afford the hearing aids that Hannah needs. I have a well paid job and by sacrificing other items we have been able to afford the approximate \$15000 it has cost us so far. Our medical insurance does not cover the cost of hearing aids.

We discovered Hannah was deaf when she was 4 years old. It came as a shock and we went through a period of grieving that our perfect daughter was "not perfect". That grieving quickly turned to determined resolve. We committed that we would get her the best technology we could so that she could hear as much as possible. Children have a tremendous capacity for learning at that young age, and Hannah was no exception. She had taught herself to lip-read, but with hearing aids in place she rapidly became more communicative and her learning curve accelerated. By the end of Kindergarten, she was a proficient reader and by the end of first grade it was obvious that she was capable of skipping a whole grade.

Each time we have upgraded Hannah's hearing aids we have been able to take advantage of improvements in technology; from analogue to digital - to 16 channels for more accurate programming - to Bluetooth compatible so she can talk on her cell phone to her friends! Each time we have seen a change in Hannah's confidence and an improvement in her ability to communicate.

We have always tried to get the best possible technology we can for Hannah, because we believe that if she is going to eventually lose her hearing and sight the more we can give her now, the more she will be able to have a fully functioning life in the future.

Without hearing aids and a great support team of teachers, audiologist and friends I don't believe Hannah would have been as successful as she has been and will be in the future.

Deafness doesn't define Hannah. To her, putting on her hearing aids in the morning is as normal as brushing her teeth or putting in her contact lenses. At times she chooses to switch off her hearing aids and live in a silent world, but it is her choice. To not be able to hear would be devastating to her as sound is part of her life. As I write this she is doing her homework across the room, listening to music; the range is amazing from Taylor Swift to Beethoven to Irish Jigs

We were disappointed when we found out that our medical insurance did not cover the cost of hearing aids for Hannah. We continue to struggle to understand how hearing aids could be on the same list of exclusions as:

- *"Elective or voluntary enhancement procedures, services, supplies and medications including but not limited to: Weight loss, hair growth, sexual performance, athletic performance, cosmetic purposes, anti-aging and mental performance unless medically necessary."*
- *"Personal convenience items, such as a telephone or television in your room at a hospital or skilled nursing facility"*

The reasons I'm supporting these bills are simple:

- Hearing Aids or Cochlear Implants are not "cosmetic" or a "convenience" item. For deaf children who want to hear they are a necessity of life.
- There are many families who can not afford to pay for the cost of the hearing equipment their child needs, as a result children are limited in reaching their full potential.

I don't ask you support these bills for Hannah, I ask you to support them for all the children who with the right support can follow Hannah's path and make their parents as proud of them as I am of Hannah.

At the end of the day this decision is about stewardship and making sure that we leave a better place than we found. We have a responsibility through our acts to make sure that we make a positive difference in people's lives in particular when they are children.

Please support Senate Bill 27 and Assembly Bill 16 requiring Insurance companies in Wisconsin to cover the cost of hearing aids and cochlear implants.

#### Contact Information

Matt Fitton  
6 South Meadows Drive  
Appleton  
WI 54915

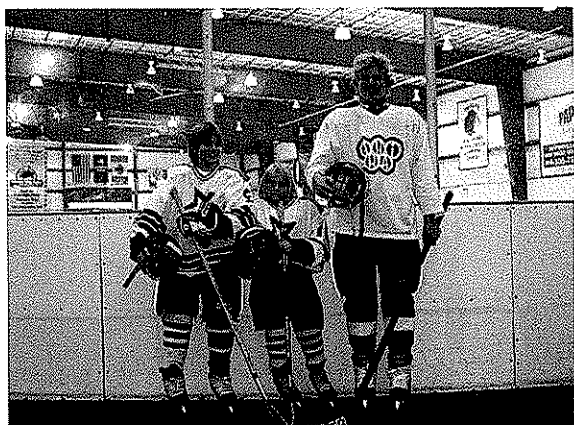
(920) 830 0515  
MTFitton@aol.com



GBR Female 400m Freestyle  
Relay

Hannah (2<sup>nd</sup> from right)

2007 World Deaf Swimming  
Championship, Taiwan



### Support for Senate Bill 27, Assembly Bill 16

My name is Connie Breaker. I am the mother of three (3) children who are moderately to severely hard-of-hearing. The three reasons this Bill is so important to me are pictured above. Eli, Ian, and Libbey are my children.

I have had to deal with insurance companies for over 16 years. Back when Eli was diagnosed in 1992, we had an HMO. This HMO covered hearing aids only if purchased through 1 hearing aid dispenser in Appleton. The audiologist we saw at Children's Hospital wrote a prescription for hearing aids for Eli. Three years later it was discovered the hearing aid dispenser (not an audiologist) ordered the WRONG strength of hearing aids. So, for three years, Eli had no benefit from these hearing aids. The HMO may have paid for the hearing aids, but the quality of the person fitting the hearing aids was poor. In 1996, Eli was 5, Ian was 3, and Libbey was born. Ian was tested every 6 months at UW-Oshkosh. His tests always came back "normal". But he was not talking yet. The fall of 1996, I made a trip to Children's Hospital with all three children for hearing tests. I left the audiologist office that day with a diagnosis of moderately severe hearing loss in all three children. Now we have a different insurance company. This insurance will only pay \$500 per hearing aid. I now had to buy 3 pairs of hearing aids (6 total). The cost of each pair was over \$3,000 dollars for each pair. Now my husband and I had to find \$6,500 so our children can hear sound. This was a hard time financially for us. It put a strain on our marriage, and stressed the family. Several years later, the audiologist now tells us that we need to buy new hearing aids. The ones we had were no longer loud enough and we had to get stronger more powerful hearing aids for all three. Again, our insurance has changed and the hearing aids are now digital and programmable and much more expensive per pair. We had to find another \$7,000 so our children can hear sounds.

You may have noticed I am stating that the children can hear sounds with the hearing aids; this does not mean they are able to hear all speech. In 2004, our audiologist states that the 2 boys are now considered cochlear implant candidates. A cochlear implant can do what a hearing aid could not for my 2 boys; allow them to hear all the speech sounds. Again our insurance has changed. This insurance company has a line item in it declaring Cochlear Implants Are Not Covered. I was devastated, angry, hurt, and just plain mad! How could they decide if my children could hear? How could they control the quality of life for my



children? I tried to fight the insurance company, I petitioned them to allow the testing for cochlear implant surgery and the surgery itself, but was told NO. I began to look at my options:

1. Divorce my husband, loose my job, and loose my house. Then my children would be taken care by Medicaid.
2. Find a job with insurance that covered cochlear implant surgery.
3. Call the place of husband's employment and beg them to buy insurance that covers cochlear implants.

How dare this insurance company to force me to look at an option that involves our family to fail. This was not an option at all. Luckily, my husband's employer was willing to purchase a plan that included cochlear implant surgery. We had to sacrifice the minimal hearing aid benefit (\$500 per ear). Again, some one else was controlling the ability for my children to hear or not hear. Both boys now have had their cochlear implants for 4 years. This was the best decision we had made as a family, and one of the most difficult. We still had to pay bills that totaled over \$4,000.

The summer of 2005 we were lucky enough to attend the American Hearing Impaired Hockey Association hockey camp. This camp bought all three children new hearing aids totally over \$11,000. This was done through a grant the camp received from some one and my children were lucky enough to benefit. This gift could not have come at a better time. The Eli and Ian needed new hearing aids and Libbey was due in the next 24 months for a new pair of hearing aids

So, I figure over the last 16 years, we have paid over \$25,000 so my three children could hear. I had to return to work full time. Our family has taken only one vacation. I would not change anything about my three children, but it has been difficult financially.

Thank you for your time,

Connie Breaker

3457 Rosenberry Ct.

Appleton WI 54913

## Franz Backus - In Favor of AB 16 and SB 27

Good morning Chairman Erpenbach, and members of the committee. Thank you for this opportunity to share my reasons in support of SB 27 And AB16

You will hear from parents who have struggled with equipping their children to join the hearing world in which you and I live. These children and their parents have poignant and real stories to tell. Having been hard of hearing since my youth, and a Cochlear Implant recipient, I too have a story about **the challenge of learning when you can't hear.**

The story that you will hear from me however is about the parents who can not afford hearing instruments for their children and could not be here because, they can not take time off, and. **the taxpayers** who foot the bill of educating the undeveloped mind of each child who is held captive in deafness at the time he or she needs to hear to learn speech and socialization skills.

I am going to tell you the economic impact of the practice of denying hearing Instruments, and Cochlear Implant insurance coverage.

By way of background the following points should be considered.

- There are about 200 children born in Wisconsin each year who are profoundly hard of hearing or "deaf" (of the "deaf" about 1/3 can not be helped by aids or Cochlear Implants)
- Children from families who do not have income are eligible for implants and hearing aids from existing health programs in the state (title 19)
- Children from families covered by state employee health care programs also have access to aids and Cochlear Implants and are not affected
- The cost of this aid and Implant coverage for example is very low, (the State of Minnesota employee coverage for all

subscribers was estimated to be \$0.25 per policy per month, and Wisconsin added aids and implants for all covered by policies, not just infants, by increasing co-pay for emergency room visits by \$15.00 per visit which had zero impact on Wisconsin taxpayers.)

- The only folks **not covered**, are those who work and thus have too much income
- An alternative for these parents who are not covered is to give up work (income) to qualify for title 19 type grants, a prospect that no one desires.

As an economist I am sorry not to have the exact number of children that would be affected, but it is very small and that is a problem. I can however tell you in Wisconsin public education there are currently 1,189 children under 11 years old who are defined as deaf or hard of hearing. Since students continue in public education until they graduate from high school one could estimate there are about 4,000 in our schools. This is a small but expensive population hidden by their being in districts across the state that hides the impact from the public, but costs taxpayers thousands of dollars each year they are in school. These students are in public schools for an average of 14 years, so it does not take too much math to conclude a savings of say \$5,000 for aids or even \$60,000 for a Cochlear Implant early in life is multiples less than the costs to taxpayers of attempting to repair the damage of denying hearing aids and Cochlear Implants.

Correctly fitted high-powered hearing aids and cochlear Implants early in life help prevent speech and learning disabilities and with them the attendant cost to the taxpayer.

The insurance industry has no incentive to add coverage that has a very low chance of occurring, but can be "costly". It does not produce many denials, and is seen as a cost savings.

The incidence of well less than 200 claims a year for newborn is too low to even offer a rider to cover implants and aids for newborns. So

even if a family wanted to buy a policy when they were adding to their family would have great difficulty doing so.

*(Insures would rightfully see such a rider as selling a 100-day term life policy for a family member being deployed to a war zone and parents would be better off buying a lottery ticket as the number requiring insurance is so low.)*

And last there is **the taxpayer** who is providing incentives to families to quit work to gain "title 19" coverage to take care of their child, and who pay for schooling children who are unnecessarily handicapped by non-coverage.

There are many experts who can discuss in real (not theoretical terms) the results of denying hearing to babies and very young children and you will hear from them. In graphic terms however denying hearing in the early years is in a very real sense equivalent to binding a child's hands for the first years of life and then sending him/her off to shop class.

No amount of fixing or remediation is going to correct the damage, but the Wisconsin Taxpayer is going to pay to attempt to, under the real and honorable effort to leave no child behind, which has been Wisconsin's rightful motto for a long time.

In short you hold in your hands the power to send possibly a 100 severely handicapped children to Wisconsin public schools each year or to send these same children reasonably enabled to attend school as normal (non-handicapped).

I am aware that all folks that petition you claim their bill is good for the state and or that it saves money, and as an economist I have made my share of such eloquent arguments using theoretical data. There is no theory that denying hearing in the earliest years cripples children, it is that simple and the effect on our schools and taxpayers is real, so we may disregard the lifelong effects on the needlessly deaf child when they reach adulthood and pay less taxes and contribute less to society than the fully educated and enabled.

Please consider the taxpayer on this issue, and that the insurance industry on an equal footing would absorb or displace the very small

sums paid to cover the few infants they would find in their covered. This is a very large impact bill. I hope now that you have been given the nature of this bill, you will send it to the your respective chambers with your full endorsement as good public policy.

Thank you for your consideration.

Franz Backus (Economist)

### **Addendum**

Starting with 200 births a year of severely hearing impaired children, and subtracting those covered by Title 19, state of Wisconsin employee covered, and those children for whom there is no possible intervention, it is possible that fewer than 100 births a year are covered by the proposed law. I do not have data on how many children suffer severe permanent hearing loss from childhood diseases, which is why I cannot reasonably estimate the actual number. It is worth noting however that insurance generally covers the diseases that can cause deafness and that the coverage stops with the drugs as if the child is cured, and this is a cruel event that hurts more than the families and the child.

The cost of providing special education to students who are deaf or had of hearing throughout their school career is impossible to generalize. I am aware of a report by AG Bell to identify the cost of educating children who are deaf as about \$420,000. This report has been widely used, but is over 12 years old and simply cannot account for the differences of children, the degree of damage to each child, and different wage contracts for professional staff.

It is not difficult however to believe that it would cost more than \$15,000 per year, per child, which produces additional taxpayer burden of \$210,000 for schooling. Given the cost to an insurance group of \$5,000 to \$60,000 for an implant and it is clear that good public policy would be to require coverage.



Date: March 18, 2009

To: Chairpersons Erpenbach and Cullen, Members of the Senate Committee on Health, Health Insurance, Privacy, Property Tax Relief and Revenue, Members of the Assembly Committee on Insurance

From: Dr. Laura J. Feldhake, Au.D, Wisconsin Speech Language Pathology and Audiology Professional Association, VP of Audiology Services

Re: 2009 Senate Bill 27/Assembly Bill 16

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Chairman Erpenbach, Chairman Cullen, and members of the committees, thank you for this opportunity to speak in favor of SB 27 and AB 16. My name is Laura Feldhake. I am a resident of Stoughton, Wisconsin, where I currently operate a private practice audiology clinic. I am here representing the Wisconsin Speech Language Pathology and Audiology Professional Association, otherwise known as WSHA-P, as the VP of Audiology Services. WSHA-P represents over 700 audiologists and speech language pathologists. I am also a parent of a child with a hearing loss that requires amplification.

The bills you have before you include the language from amendments that were proposed last session. The bills also include a more inclusive definition of what a cochlear implant is and require health insurance coverage for hearing aids and cochlear implants for children under the age of 18, rather than under the age of 11 years. This change was proposed as the financial burden of purchasing hearing devices does not decrease as a child ages, nor does the susceptibility of acquiring a hearing loss that requires amplification.

Over a decade ago, I was privileged to participate in the development of the Wisconsin's newborn hearing screening initiative. At that time, many stakeholders felt that intervention should be part of a newborn hearing-screening proposal arguing, "why screen for something that is not required to be covered by insurance?" Ultimately the consensus was to first detect and then correct. The hope being that correction would come sooner than later. Unfortunately, here we are over a decade later and the "correct" part has yet to be addressed. Why provide newborn hearing screening but not require insurance coverage for appropriate early intervention for hearing loss?

The main purpose of screening hearing is so intervention can start earlier in life. Without intervention, language development will be delayed. Language is used for a range of functions in school and in everyday life. Without proper access to language, children are at risk for development delays, which translate into higher education costs, reduced employment capabilities, and an increase in long term costs to the general population. Research tells us that earlier intervention for hearing loss results in lower costs for services an individual with a hearing loss will need. Knowing this, why wait to begin intervention? Many parents answer

this question by saying “we would have begun treatment sooner if we could afford the process.”

I would like to speak briefly about the reasoning beyond changing the minimum age for insurance coverage from 11 to 18 years of age. There are many documented childhood progressive hearing loss processes that do not require amplification upon diagnosis but will require amplification as the hearing loss develops. My own daughter did not require amplification for her hearing loss until the age of 11 years when it had progressed enough to interfere with her classroom learning. Language development occurs well beyond the early years. Between the ages of 5 and 11 years, children learn on average 3000 to 5000 new words each year and are developing more complex aspects including reading and writing. Beyond 11 years, teens are learning to comprehend metaphors, idioms, sarcasm, and figurative language. They become less literal and more abstract in their descriptions. Without treatment and ongoing intervention, these skills will not develop correctly, which directly impacts their interactions with peers, family, instructors, and future employers.

Many states already require insurance coverage for hearing aids and cochlear implants and several more have legislation pending, including Illinois. We, as a state, are doing terrific compared to other states with lowering the age of identification, but we are behind with lowering the age of intervention.

In conclusion, I ask committee members to please to support SB 27 and AB 16. Thank you for allowing me to testify before you today. I will be happy to answer any questions.

Date: March 18, 2009

To: Chairpersons Erpenbach and Cullen, Members of the Senate Committee on Health, Health Insurance, Privacy, Property Tax Relief and Revenue, Members of the Assembly Committee on Insurance

From: Dr. Cindy Grant-See, Au.D

Re: 2009 Senate Bill 27/Assembly Bill 16

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Thank you, Chairpersons Erpenbach and Cullen, and members of the respective committees for allowing me to submit written testimony in support of 2009 Senate Bill 27 and Assembly Bill 16. My name is Cindy Grant-See, and I am an audiologist at Marshfield Clinic.

In the state of Wisconsin, over 95% of hospitals are screening newborns for hearing loss. Data particularly from Yoshinaga-Itano (1998) has found babies who are diagnosed soon after birth and have the benefit of early intervention are able to make up the milestones of speech and language development and be on target with their normal hearing peers when they enter kindergarten. This is very remarkable!

Prior to newborn hearing screening, children typically were not identified with hearing loss until two to four years of age, when speech and language was already significantly delayed. Even with significant intervention throughout the school years at great expense, the later identified children continue to demonstrate not only speech and language delays but cognitive, academic, and social delays at tremendous cost to society.

The reason for screening babies for hearing loss is to intervene. A considerable part of the intervention process is appropriate amplification (hearing aids) or in cases of severe and profound hearing loss, cochlear implantation.

Currently, through a grant from the Maternal and Child Health Bureau, the state of Wisconsin has formed a statewide learning collaborative effort to get babies who refer on the newborn hearing screening, diagnosed by three months of age, and enrolled in early intervention services by six months of age. Participants in the collaborative effort include: staff and physicians from the newborn nurseries, primary care providers, audiologists, genetic counselors, ENTs, Birth-Three case workers, and parents. Part of this process is securing appropriate amplification in a timely manner. This bill goes a long way in support of this effort!

It is becoming more and more of a challenge to secure funding for appropriate hearing aids for children. The funding for Wisconsin's program for Children with Special Healthcare needs dried up 10 years ago. The Wisconsin Lions Hearing Aid Program and Children's Miracle Network have experienced budget constraints over the years, limiting the funds available to get appropriate hearing aids for children.



In this age of miniaturization of technology, many of the school systems rely on the children's personal hearing aids or cochlear implants to link with the classroom amplification (FM) systems. More and more hearing aids are also beginning to use blue tooth technology which will benefit many children with hearing loss in the years to come.

So while this bill may cause a slight increase in insurance premiums, the potential savings are in the educational system where a child with hearing loss will arrive in kindergarten on target with his or her normal hearing peers. In addition, a child with appropriate amplification/cochlear implantation throughout the school years will be able to take full advantage of all educational opportunities.

Thank you for scheduling a public hearing on these important bills.

Respectfully,  
Cynthia See, Au.D.  
Audiologist  
11778 Hwy 73  
Pittsville WI 54466  
715-884-6944



Emily (6)

Josie (7)

My name is Vicki Denzin. I am the parent of 2 children with mild to moderate sensorineural hearing loss. Both girls, when not wearing their hearing aids, only hear about 80% of normal conversation. Imagine going through school and only hearing 80% of what is being taught to you, 80% of what your friends are trying to share with you, 80% of your spelling test. And my girls only have mild to moderate hearing loss. Hearing aids enable my daughters to hear what you and I take for granted.

One week before my daughter Josie received her hearing aids, her kindergarten class had a fieldtrip at Heckrodt Wetland Reserve in Menasha, WI. Josie was unable to hear the frogs croaking, the birds chirping or even the crickets. It broke my heart to see her struggle to hear what her classmates were being taught that day and she couldn't hear it. The day she got her hearing aids was a wonderful hearing celebration. "It sounds like microphones in my ears" is what her first comment was. What joy to watch her hear sounds she has never heard before. "What's that?" was often the catch phrase for the next few weeks. The rain pounding against the window, the rustling of leaves blowing in the wind, crickets in the grass, even the buzz of the dishwasher completing its job.... All sounds I didn't know she missed out on.

PLEASE SEE THE ATTACHMENT, A STORY WRITTEN BY JOSIE, A FIRST GRADER. THE IDEA FOR THE STORY WAS HERS. IT WAS WRITTEN EARLIER THIS YEAR.

Fortunately, for my two daughters, my husband and I have good credit and access to credit cards in order to pay off the expense of hearing aids. We also put our pride aside and had our parents assist us.

We paid \$7000 last year for both girls to obtain their pair of hearing aids. Our insurance paid for the audiology exam and the ENT appointment, nothing for the hearing aids or ear molds required for the hearing aids. We are told hearing aids need to be repurchased, with any luck, only every 5 years. Ear molds are \$150 for each year and are replaced about 1x a year, based on growth. The younger the child, obviously the more frequent the ear mold change. If this expense wasn't bad enough... we had just moved to Wisconsin and were feeling the housing crunch, trying to afford 2 mortgage payments while we were waiting for our old house to sell. We are fortunate. We were able to come up with a way to get the hearing aids my daughters needed so they can continue to excel at school and socially with their peers. I hate to think about how many parents are faced with this dilemma and are unable to provide their children with what is needed to ensure a proper foundation to a lifetime of learning and achievement.

We live in a hearing world. There is no debate about that. However, every child deserves the right to hear, regardless of the expense. This is why we need you, our government officials, to look out for our children and all children of our state and support this bill. Hearing aids are not cosmetic, as the insurance companies state in their denials. As you are well aware of the statistics stated previously, hearing aids ensure speech and language development and assist these children in their education. Without the aids, children with hearing impairments function at least 1-4 grade levels lower than their peers. Hearing aids and cochlear implants are *medically necessary* to improve the chances of these children in achieving their dreams, in leading successful, prosperous careers. No one should be told they cannot pursue an education or career due to the inability to hear. More importantly, the lack of ability or difficulty of the parents to afford such technology should not stand in the way of completing high school, college or graduate school. What would you want for your children, your grandchildren.... If you can look my daughters in the eye and tell them that they don't NEED or deserve the technology out there to succeed and pursue their American Dream, then I know how you stand... I am positive that no one in this room is able to do that. I urge you to look at the children before you today and think about the children in your life when you cast your vote. I am optimistic that you will do the right thing and support Senate Bill 27 and Assembly Bill 16.

Thank you for your time!



Vicki Denzin

Neenah, WI

# Getting My Hearing Aids

By Josie Denzin (7 yr old)

1<sup>st</sup> grader at Tullar Elementary, Neenah

I had to get hearing aids. I was scared. I had to get stuff squirted in my ears. It was cold.

A couple of days later, I got my hearing aids. When I put them in, it sounded like everything was in a microphone. It felt like it was plugging my ears, but I could still hear.

I was nervous to go to school the next day. My mom said "Happy first day of school with your hearing aids!"

I was worried about what the kids were going to say. Mrs. Schumacher explained to the kids that I needed hearing aids to help me hear.

My mom showed the kids what they looked like. At snack time, we had cupcakes to celebrate. One of the kids asked if they could touch it and they could not.

At the end of the day, I felt better about the questions that the other students would ask.